



Facing the Challenges of Chronic Kidney Disease in Children

How can chronic kidney disease (CKD) affect children and their families?

The lives of children with serious and long-lasting conditions such as CKD are affected in many ways. CKD is any condition that causes reduced kidney function over an extended period of time. Children with CKD may have a negative self-image and may have relationship problems with family members due to the stress of living with a chronic disease. The condition can lead to behavior problems and make participating in school and extracurricular activities more difficult. CKD can cause learning problems because the buildup of wastes in the body can slow down nerve and brain function. Children with CKD may have trouble concentrating and may develop language and motor skills more slowly than their peers. The most severe problems occur when CKD is present starting early in infancy.

CKD that leads to kidney failure—described as end-stage kidney disease or ESRD when treated with a kidney transplant or blood-filtering treatments called dialysis—can increase these challenges. Fortunately, a kidney transplant can reverse or improve most of these problems. Dialysis can also improve or correct these problems. Most children with CKD who receive appropriate treatment can attend school, graduate from high school, and go on to college or vocational school. However, families of children with CKD or kidney failure need

to recognize that these children may need additional guidance and understanding.

Read more about kidney disease in children and its treatment in *Overview of Kidney Diseases in Children* and *Treatment Methods for Kidney Failure in Children* at www.kidney.niddk.nih.gov.

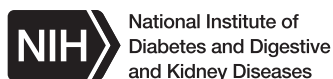
How can parents and other adults help children with chronic kidney disease in daily life?

Parents and other adults can help children with CKD fit in at school, deal with low self-esteem, make friends, be physically active, and follow their treatment regimen. As children with CKD approach adulthood, they may need help with preparing to enter the workforce.

Attending School

School attendance is vital in helping children with CKD lead the best life possible. Many people are unaware of how CKD affects children. School administrators, teachers, and classmates should receive education and information about the effects of CKD.

Children with kidney failure may miss school each week because of dialysis and medical appointments. These absences can compound the learning problems many children with CKD face. Parents or guardians should make every effort to schedule treatments outside of school hours.



National Kidney and Urologic Diseases
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The Individuals with Disabilities Education Act Public Law 94-142 states that every child is entitled to an appropriate education and directs school districts to provide special services to ensure children with disabilities can participate in regular classrooms to the fullest extent possible. Children with CKD may need

- tutoring
- vocational rehabilitation
- special accommodations

To receive special education services, children must be evaluated to see if they have a disability and must receive an Individualized Education Program—a written document that details the services each child will receive. Parents or guardians of children with CKD should talk with the school counselor about having their child evaluated.

Dealing with Low Self-esteem

Having a chronic illness can make a child feel depressed and powerless. Learning and growth problems may also contribute to low self-esteem. One way to help children feel empowered is to give them as much control and responsibility over their own care as possible:

- Children can learn more about their medications, including doses.
- Children on dialysis should be encouraged to take an active part in their treatments.
- Parents or guardians should allow children to participate in treatment decision making.

Urinary incontinence—the loss of bladder control, which results in the accidental loss of urine—is common in children with CKD. Urinary incontinence can be embarrassing for children and can make it harder to build relationships with their peers. However, several strategies and treatment options are available to help prevent urinary incontinence.

Read more in *Urinary Incontinence in Children* at www.urologic.niddk.nih.gov.

Making Friends

Children with CKD may have trouble fitting in with children their own age because of their small stature or delayed mental development. For children who have had a transplant, the side effects—such as a full face, weight gain, acne, or facial hair—of some of the medications they take may make it harder to make friends and may also lower self-esteem. Participating in regular classroom and extracurricular activities may help children improve their social skills. Summer camps and recreational programs for children with special needs can be a good place to make new friends.

Participating in Physical Activities and Sports

Children with CKD should be encouraged to participate in physical activities, including exercise and sports. In general, exercise has physical and psychological benefits. Parents or guardians may feel protective of children with CKD; however, they should not try to limit activities unless instructed to by a health care provider. Some children may even need to be encouraged to get outside and play. Parents or guardians should talk with their child's health care provider about the right activity level and appropriate sports for their child.

Children who have had a kidney transplant can compete in sports. Every year the Transplant Games, sponsored by the National Kidney Foundation, allow people with transplants to participate in friendly competition and show the world that transplantation provides a new lease on life and health.

Following Treatment Regimens

Children with CKD may need to take multiple medications, eat a specific diet, and follow their health care provider's orders to help control their disease. Many children have a hard time following the treatment regimen. Health care providers use the term nonadherence to describe the failure or refusal to take prescribed medications or follow a

health care provider's directions. Adherence can be improved with a combination of health education, motivational techniques, and behavioral skill methods. Strategies need to be tailored to each child and the child's family. The health care provider should

- teach the child about the condition and treatment regimen
- talk with the child to learn about the child's wishes, beliefs, and feelings to find ways to improve motivation
- suggest methods for remembering to take medications, such as a calendar, a pillbox, or text message reminders

Preparing to Enter the Work Force

Young adults who have been treated for CKD during childhood have to overcome a number of barriers to prepare for a career and find a job. Completing the training required for employment takes more effort, and some people with CKD report that their small stature creates problems fitting into adult environments. Employers may have trouble understanding kidney problems and the accommodations that need to be made for people with CKD. The employment section of the U.S. Department of Labor's Disability website offers a variety of resources for employers and job seekers about career planning, workplace accommodations, work incentive programs, and other related issues.

Who can help families deal with issues related to chronic kidney disease in children?

Many skilled professionals are available to ensure that children with CKD get the best possible care. The family may want to talk with a social worker, mental health professional, financial counselor, and dietitian. If a child reaches kidney failure, the medical staff at the dialysis center or transplantation clinic can provide help.

Social Worker

A social worker can help families locate services such as transportation and family counseling. The social worker can provide information about

- finding support groups in the community
- helping a child with a chronic illness rejoin school activities
- reducing the stress of caring for a child with a chronic illness

The social worker can also help families submit applications for Medicare and Medicaid. Medicare is a program that helps people older than 65 and people with disabilities, including people of any age with kidney failure, pay for medical care. Medicaid is a health care program for certain low-income individuals and families who fit into an eligibility group that is recognized by federal and state law.

Mental Health Professional

A mental health professional, such as a psychologist, can help children with CKD find ways to deal with the emotional turmoil caused by having a chronic illness. Some child psychologists also specialize in helping children with disabilities and medical problems rejoin school activities. They may also be able to suggest techniques that reinforce adherence with taking medication and following the health care provider's instructions.

Family members may also find that counseling helps them handle the conflicts and stresses they face. Many couples report increased tension in their marriage when their child has a serious illness such as CKD. Siblings may resent the amount of attention given to their sibling with CKD and feel guilty about having bad thoughts about their sibling.

Financial Counselor

A financial counselor can help families meet the financial obligations that chronic illness creates. Medical bills can strain family finances; in some cases, a parent or guardian may need to stop working to care for a child full time.

Read more in *Financial Help for Treatment of Kidney Failure* at www.kidney.niddk.nih.gov.

Dietitian

Proper nutrition is extremely important for children with CKD. Every dialysis clinic has a dietitian to help people understand how the food they eat affects their health. The dietitian

- helps develop meal plans to fit a child's restricted diet
- provides information about possible nutritional deficiencies caused by kidney disease
- recommends special dietary supplements or formulas to improve the child's nutrition
- provides recipes and recommends cookbooks appropriate for people with kidney disease

Following the restrictions of a kidney disease diet might be hard at first; however, making tasty and satisfying meals is possible with just a little creativity.

Eating, Diet, and Nutrition

For children with CKD, learning about nutrition is vital because their diet can affect how well their kidneys work. Parents or guardians should always consult with their child's health care team before making any dietary changes. Staying healthy with CKD requires paying close attention to the following elements of a diet:

- **Protein.** Children with CKD should eat enough protein for growth while limiting high protein intake. Too much protein can put an extra burden on the kidneys and cause kidney function to decline faster. Protein needs increase when a child is on dialysis because the dialysis process removes protein from the child's blood. The health care team recommends the amount of protein needed for the child. Foods with protein include
 - eggs
 - milk
 - cheese
 - chicken
 - fish
 - red meats
 - beans
 - yogurt
 - cottage cheese

- **Sodium.** The amount of sodium children need depends on the stage of their kidney disease, their age, and sometimes other factors. The health care team may recommend limiting or adding sodium and salt to the diet. Foods high in sodium include

- canned foods
- some frozen foods
- most processed foods
- some snack foods, such as chips and crackers

- **Potassium.** Potassium levels need to stay in the normal range for children with CKD, because too little or too much potassium can cause heart and muscle problems. Children may need to stay away from some fruits and vegetables or reduce the number of servings and portion sizes to make sure they do not take in too much potassium. The health care team recommends the amount of potassium a child needs. Low-potassium fruits and vegetables include

- apples
- cranberries
- strawberries
- blueberries
- raspberries
- pineapple
- cabbage
- boiled cauliflower
- mustard greens
- uncooked broccoli

High-potassium fruits and vegetables include

- oranges
- melons
- apricots
- bananas
- potatoes
- tomatoes
- sweet potatoes
- cooked spinach
- cooked broccoli

■ **Phosphorus.** Children with CKD need to control the level of phosphorus in their blood because too much phosphorus pulls calcium from the bones, making them weaker and more likely to break. Too much phosphorus also can cause itchy skin and red eyes. As CKD progresses, a child may need to take a phosphate binder with meals to lower the concentration of phosphorus in the blood. Phosphorus is found in high-protein foods. Foods with low levels of phosphorus include

- liquid nondairy creamer
- green beans
- popcorn
- unprocessed meats from a butcher
- lemon-lime soda
- root beer
- powdered iced tea and lemonade mixes
- rice and corn cereals
- egg whites
- sorbet

■ **Fluids.** Early in CKD, a child's damaged kidneys may produce either too much or too little urine, which can lead to swelling or dehydration. As CKD progresses, children may need to limit fluid intake. The health care provider will tell the child and parents or guardians the goal for fluid intake.

Read more in *Nutrition for Chronic Kidney Disease in Children and Kidney Failure: Eat Right to Feel Right on Hemodialysis* at www.kidney.niddk.nih.gov.

Points to Remember

- Children with chronic kidney disease (CKD) may have a negative self-image and may have relationship problems with family members due to the stress of living with a chronic disease. The condition can lead to behavior problems and make participating in school and extracurricular activities more difficult.
- CKD can cause learning problems because the buildup of wastes in the body can slow down nerve and brain function. Children with CKD may have trouble concentrating and may develop language and motor skills more slowly than their peers.
- Parents and other adults can help children with CKD fit in at school, deal with low self-esteem, make friends, be physically active, and follow their treatment regimen. As children with CKD approach adulthood, they may need help with preparing to enter the workforce.
- School attendance is vital in helping children with CKD lead the best life possible.
- One way to help children feel empowered is to give them as much control and responsibility over their own care as possible:
 - Children can learn more about their medications, including doses.
 - Children on dialysis should be encouraged to take an active part in their treatments.
 - Parents or guardians should allow children to participate in treatment decision making.
- Participating in regular classroom and extracurricular activities may help children improve their social skills. Summer camps and recreational programs for children with special needs can be a good place to make new friends.
- Parents or guardians may feel protective of children with CKD; however, they should not try to limit activities unless instructed to by a health care provider.

- Children with CKD may need to take multiple medications, eat a specific diet, and follow their health care provider's orders to help control their disease. Many children have a hard time following the treatment regimen. Health care providers use the term nonadherence to describe the failure or refusal to take prescribed medications or follow a health care provider's directions.
- Adherence can be improved with a combination of health education, motivational techniques, and behavioral skill methods.
- Many skilled professionals are available to ensure that children with CKD get the best possible care. The family may want to talk with a social worker, mental health professional, financial counselor, and dietitian. If a child reaches kidney failure, the medical staff at the dialysis center or transplantation clinic can provide help.
- For children with CKD, learning about nutrition is vital because their diet can affect how well their kidneys work. Parents or guardians should always consult with their child's health care team before making any dietary changes.

Hope through Research

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) conducts and supports research to help people with kidney diseases, including children. The NIDDK, in collaboration with the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development and the National Heart, Lung, and Blood Institute, funded the formation of a cooperative agreement between two Clinical Coordinating Centers and a Data Coordinating Center to conduct a prospective epidemiological study of children with CKD. The primary goals of the Chronic Kidney Disease in Children Prospective Cohort Study (CKiD) are to

- determine the risk factors for decline in kidney function
- define how a progressive decline in kidney function affects neurocognitive function and behavior
- determine risk factors for cardiovascular disease
- assess growth failure and its associated morbidity

More information about the CKiD, funded under National Institutes of Health (NIH) clinical trial number NCT00327860, can be found at www.statepi.jhsph.edu/ckid.

Clinical trials are research studies involving people. Clinical trials look at safe and effective new ways to prevent, detect, or treat disease. Researchers also use clinical trials to look at other aspects of care, such as improving the quality of life for people with chronic illnesses. To learn more about clinical trials, why they matter, and how to participate, visit the NIH Clinical Research Trials and You website at www.nih.gov/health/clinicaltrials. For information about current studies, visit www.ClinicalTrials.gov.

For More Information

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c/o Medical Education Institute, Inc.
414 D'Onofrio Drive, Suite 200
Madison, WI 53719
Phone: 1-800-468-7777 or 608-833-8033
Fax: 608-833-8366
Internet: www.lifeoptions.org
www.kidneyschool.org

National Kidney Foundation

30 East 33rd Street
New York, NY 10016
Phone: 1-800-622-9010 or 212-889-2210
Fax: 212-689-9261
Internet: www.kidney.org

United Network for Organ Sharing

P.O. Box 2484
Richmond, VA 23218
Phone: 1-888-894-6361 or 804-782-4800
Fax: 804-782-4817
Internet: www.unos.org

Resources

American Society of Transplantation

Facts about Kidney Transplantation: Pediatric Patient Education Brochure
www.myast.org/sites/default/files/images/2_FACT%20ABOUT%20KIDNEYTRANSPLANTATION%20%20FINAL.pdf

National Kidney Foundation

Children with Chronic Kidney Disease: Tips for Parents
www.kidney.org/atoz/content/childckdtdtips.cfm

Family Focus newsletter

www.kidney.org/patients/pfc/backissues.cfm

Employers' Guide

www.kidney.org/atoz/content/employersguide.cfm

Nemours KidsHealth Website

When Your Child Has a Chronic Kidney Disease
www.kidshealth.org/parent/medical/kidney/chronic_kidney_disease.html

What's the Deal with Dialysis?

www.kidshealth.org/kid/feel_better/things/dialysis.html

Nephkids

Cyber-support group
www.cybernephrology.ualberta.ca/nephkids

United Network for Organ Sharing

Organ Transplants: What Every Kid Needs to Know
www.unos.org/docs/WEKNTK.pdf

U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services

Medicare Coverage of Kidney Dialysis & Kidney Transplant Services
www.medicare.gov/Publications/Pubs/pdf/10128.pdf

U.S. Social Security Administration

Benefits for Children with Disabilities
www.socialsecurity.gov/pubs/EN-05-10026.pdf

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The National Kidney Disease Education Program (NKDEP) is an initiative of the National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health, U.S. Department of Health and Human Services. The NKDEP aims to raise awareness of the seriousness of kidney disease, the importance of testing those at high risk, and the availability of treatment to prevent or slow kidney disease.

You may also find additional information about this topic by visiting MedlinePlus at www.medlineplus.gov.

This publication may contain information about medications and, when taken as prescribed, the conditions they treat. When prepared, this publication included the most current information available. For updates or for questions about any medications, contact the U.S. Food and Drug Administration toll-free at 1-888-INFO-FDA (1-888-463-6332) or visit www.fda.gov. Consult your health care provider for more information.

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www.kidney.niddk.nih.gov.



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